

# nih record



**ABOVE** • Acclaimed pianist Adam György recently made his second appearance at the Clinical Center. See story on p. 11.

## features

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### 'The Richest Trip'

## Playwright Conducts Own 'Study' of Health Care, Reveals Results in Performance

By Carla Garnett

**I**t was as though Anna Deavere Smith had taken a grand tour of health care and brought back slides to share. Only instead of the usual quaint travel landscapes, the images Smith captured were 3D—actual people who talked and gestured. The characters she met laughed and sighed. One ranted and another even told off-color



jokes—right on stage in Masur Auditorium. And each one sounded unique, but looked exactly like the performer who embodied them.

A playwright who's also acted on stage and screen for some 40 years, Smith said she's been searching for American characters since the 1970s. For her latest project—*Let Me Down Easy*, a one-

SEE **PLAYWRIGHT**, PAGE 6

*On a visit to NIH, playwright Anna Deavere Smith performs excerpts from her latest play.*

### Determination, Willpower Crucial

## Employee Nearing Goal in Weight-Loss Battle

By Valerie Lambros

Pretty soon, Ronald M. Thomas will be less than half the man he used to be and he's thrilled about it.

A government employee who works as a housekeeper in the 5 East laboratories of the Clinical Research Center, he is on a mission to lose 220 pounds. He's about 40 pounds away and continues to chip away, bit by bit. Looking at him now, it's hard to believe Thomas, who stands 6'1", weighed 420 pounds at his peak and once wore size 6X clothing.

"I had high cholesterol, high blood pressure, I felt tired all the time, I sweat all the time, I didn't feel like doing anything," he said.

His feet and ankles were strained by the pressure on them. He wore a brace to keep one ankle from buckling. His eyes always looked bloodshot and his doctor warned him that he was pre-diabetic. In his late 40s, Thomas's

SEE **WEIGHT LOSS**, PAGE 4

## Symposium Honors 100th Anniversary of Sickle Cell Paper

By Carol Torgan

One hundred years ago, physician James Herrick discovered something unusual in a sample of blood taken from one of his patients, Walter Clement Noel. While healthy red blood cells look like donuts without a hole, Noel's cells were misshapen.

This observation led to Western medical literature's first description, published in 1910, of what would come to be known as sickle cell disease. To mark the 100th anniversary of the paper, several hundred scientists, clinicians and members of the public gathered late last fall on the NIH campus for the James B. Herrick Symposium—Sickle Cell Disease Care and Research: Past, Present and Future. Special guests included James Gilbert, grandson of James Herrick, and Nancy Irons, granddaughter of Dr. Ernest E. Irons, Herrick's intern who reported the patient's blood test.

"As the first molecular disease, sickle cell dis-

SEE **SICKLE CELL**, PAGE 8



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## briefs

### STEP Forum on Communicating Powerfully

The staff training in extramural programs (STEP) committee will present a Workplace Strategies forum on the topic "Look Who's Talking: Communicating Your Message Fearlessly and Flawlessly," on Tuesday, Mar. 1, from 8:30 a.m. to 1 p.m. in Masur Auditorium, Bldg. 10.

Ever look out into the audience during your presentation and notice that everyone is busy tapping away on their BlackBerrys? How do you capture and hold your audience's attention? What should be on your slides, how much text, which font and what about illustrations? NIH has important information to share with the world. Come to this forum to learn how to dazzle your audience with any topic, from scientific data to administrative policy. You are an expert in your field—now be an expert communicator.

### Sittig To Speak on Clinical Decision Support, Mar. 2

NLM's Extramural Programs Informatics Lecture Series for the 175th Anniversary will feature Dr. Dean Sittig, who will present "Clinical Decision Support: What Is It? Why Is It So Hard? What Can We Do About It?" on Wednesday, Mar. 2 at 2 p.m. at Natcher Bldg., balcony A.



Sittig is a professor at the University of Texas School of Biomedical Informatics in Houston. He is interested in all aspects of clinical information system design, development, implementation and evaluation. In addition to his work on measuring the impact of clinical information systems on a large scale, he is working to improve our understanding of both the factors that lead to success as well as the unintended consequences associated with computer-based clinical decision support and provider order-entry systems.

The lecture will also be available through NIH videocast. Light refreshments will be provided following the lecture.

### Circus Premiere Night Benefits NIH Children's Charities, Mar. 23 at Verizon Center

Ringling Bros. and Barnum & Bailey Circus will bring the 140th edition of "The Greatest Show on Earth" to Verizon Center on Wednesday, Mar. 23. The 14th annual Children's Premiere Night, hosted by R&W and benefiting the NIH Charities, begins with a free pre-show at 6 p.m. followed by the main event at 7. Tickets are on sale at the R&W activities desk in Bldg. 31, Rm. B1W30 or by calling (301) 496-4600. Orders can be placed for tickets at any R&W store. Tickets available include Circus Celebrity—front row/interactive seating where you become part of the show \$80 (reg. \$110), front row \$53 (reg. \$75), VIP \$39 (reg. \$52), section 111 & 112 (best seats) \$24 (reg. \$35).

### Orioles and Nationals Baseball Ticket Sales

The R&W will once again offer tickets to Baltimore Orioles and Washington Nationals baseball games. Orioles' tickets go on sale Tuesday, Mar. 1 in Bldg. 31, Rm. B1W30 (outside the R&W gift shop) at 8 a.m. Available are two regular season tickets (2 seats behind first base—section 14BBB seats 7-8) and tickets for 13 Sunday games (4 seats behind third base—section 58MM). You may buy one set of tickets the first time through the line. After the initial line ends you may come through again to purchase additional tickets. Arrive early to get in line if you have a particular game in mind.

Nationals' tickets go on sale on Thursday, Mar. 3 outside the Bldg. 31 R&W gift shop, also at 8 a.m. R&W has 4 seats in section 219, row D. The process to purchase tickets will be the same as for Orioles tickets. You must be a 2011 R&W member to buy tickets. Membership is \$7 for the year and can be purchased at the same time you get tickets.

### Sailing Association Open House, Mar. 3

The NIH Sailing Association invites everyone to its open house on Thursday, Mar. 3 from 5 to 8 p.m. at the FAES House at the corner of Old Georgetown Rd. and Cedar Ln. Would you like to learn to sail? Can you imagine being part of a group of skilled sailing instructors, enthusiasts and boat owners? The club offers instruction, sailboats for charter, racing, cruises, parties and fun. Open house is \$5 at the door and includes pizza and snacks; cash bar for beer and wine, \$1 each. Look for NIHA posters and flyers around campus. For more information, visit [www.recgov.org/sail](http://www.recgov.org/sail).



## Conference for Underrepresented Students Reaches 10-Year Milestone

By Jilliene Mitchell

One by one, a cluster of students boarded AirTran Airways flight 495 headed from Baltimore to Charlotte, N.C. With posters in hand, they soon joined thousands of other students who, like them, came prepared to present their research before their peers, faculty administrators and members of the scientific community at the Annual Biomedical Research Conference for Minority Students (ABRCMS) 10th anniversary event.

The recent conference provided a forum for students to network as well as an opportunity to showcase their research, attend professional development workshops, listen to scientific talks and visit exhibit booths. The meeting also gave faculty members a chance to support their students, learn about funding opportunities and obtain information about training and mentoring.

ABRCMS, which is sponsored by NIGMS and managed by the American Society for Microbiology (ASM), is the nation's largest professional conference for students underrepresented in biomedical and behavioral science fields. Packed with activities, the conference equips students with tools to help them prepare to be future leaders in the biomedical research workforce.

This year's meeting kicked off with a keynote address by Juan Sepúlveda, director of the White House Initiative on Educational Excellence for Hispanic Americans. The third Hispanic to earn a Rhodes scholarship, he informed students that he was proud of what they had accomplished thus far, but warned that they had to continue moving forward.

ASM past president and ABRCMS chairperson Dr. Clifford Houston closed the opening event with a message for students to seize opportunities presented at the meeting, absorb information and attend sessions that applied to their fields. "Students, this is your conference, own it," he said. "If you do this for yourself, you will help establish a foundation for a successful future. As a result of coming to ABRCMS, you will need to give back. Do this by participating in the scientific workforce and replacing the baby boomers."

At the 10th anniversary awards ceremony, Dr. Jeremy Berg, NIGMS director, stressed the importance of overcoming obstacles, fulfilling dreams and paying it forward. Citing the late Randy Pausch's book *The Last Lecture*, he



NIGMS director Dr. Jeremy Berg (l) talks to students following the 10th anniversary dinner of the Annual Biomedical Research Conference for Minority Students.

described the timeline of events that led to his own career and the barriers he faced. "Brick walls don't stop us, but show us how badly we want something," he said.

Berg recalled that his earlier dreams were to play sports at a high level, see atoms and repay his teachers—all of which he's accomplished. "Think about your own dreams and chart a course to achieve them," he advised.

Many of the speeches led to further discussions in the exhibit hall, where students had the chance to mingle with speakers including NIH director Dr. Francis Collins, who discussed research advances, health care reform and NIH-funded programs for underrepresented groups.

The exhibit hall served not only as a "backstage" location for students to meet celebrity scientists, but also as a place where they could meet recruiters for graduate programs, obtain information about internships and find out about funding opportunities. NIH was well represented among the exhibitors, with booths from NIAID, NIAMS, NIBIB, NIDCR, NIGMS, NIMH, NINDS, NHLBI, the Office of Intramural Training and Education and the NIH Oxford-Cambridge Scholars Program.

"I was an undergraduate student at the University of Delaware the first two times I attended ABRCMS," said Nicole Barkley of the University of Maryland, Baltimore County. "This is my first time attending as a graduate student—and I actually found out about the graduate program that I'm currently in at this meeting. ABRCMS not only helps with networking, it also helps students realize that they are not the only people doing research and that there are other people who are interested in their doing research."

The final day of the conference featured a luncheon with an address by renowned poet Dr. Maya Angelou, who advised students to incorporate art with science and stressed the importance of helping humankind. Like Angelou, Houston said that he hoped students departing the meeting would improve society by helping eliminate health disparities and becoming the next generation of scientists who will serve a dynamic and diverse U.S. population.

"ABRCMS brings out some of the best and brightest students in the country," said Houston. "It's my goal that 50 percent of the seniors who've attended this conference will move from scientists in training to scientists in the community." 🐼

## WEIGHT LOSS

CONTINUED FROM PAGE 1



**Above, l:**  
*Ronald M. Thomas shows how his old clothes no longer fit now that he has lost so much weight.*

PHOTO: COURTESY RONALD THOMAS

**Above, r:**  
*He now swims inside shirts that used to fit.*

PHOTO: VALERIE LAMBROS

body was giving out on him.

He didn't always struggle with weight. Though he'd been active and fit in his childhood, after finishing school he no longer had a regular routine that included playing ball or running around with his friends. The weight packed on, sometimes 30 or 40 pounds a year. His doctor suggested he consider bariatric surgery. He refused.

One day, he forced himself to look in the mirror and face the facts.

"I really looked at myself, and I said, 'Nah, this is not me,'" he said. "I knew I was going to have to get the weight off or I was going to be dead."

So he started to lose weight in December 2009. The first things to go were sweets—no more candy, sodas and nightly helpings of butter pecan ice cream with a slice of pound cake. In place of soft drinks, Thomas now drinks at least 120 ounces of water a day. Instead of eating junk food, he carefully reads food labels for calories and carbohydrates. He will not eat anything that has been fried and peels the skin off his baked chicken and turkey. He weighs everything he eats and allows himself only one small piece of red meat a month. A snack now means a teaspoon of peanuts.

He's also incorporated exercise into his routine. At a gym near his Maryland home, he rides a stationary bike and spends time on an elliptical machine while listening to jazz on his iPod. He also does 200 sit-ups every night.

For Thomas, the first week was the hardest, but as he moved into his second week and got accustomed to his new habits, he started to see the first effects of his diet plan.

"I felt it first in my feet," he said. "I woke up in the morning and my feet weren't swollen."

Though he hadn't told anyone about his plan to drop weight, others began noticing a change in him, including Dr. Gregory Kato, a pulmonary hypertension specialist with NHLBI who works on sickle cell disease in the 5 East labs.

"In the first couple months of him dieting and losing weight, he started to fill me in on the factors that made him want to do this," Kato remembers. "He just had one of those watershed moments and decided, 'From this point on, that isn't what I want my life to be,' and there's never been a consideration of going back in his mind. It's the domination of willpower. He's an inspiration."

Another milestone came when Thomas was out



running errands. While at Walmart, he decided to pick up a shirt and tried one on. It fit.

"It was unbelievable," he said. "I realized I could go to a regular store to buy clothes. Before, I always had to go to a big and tall store."

He now has a closet full of clothes to get rid of, as well as most of his shoes. In addition to shrinking out of his size 58 pants and 6X tops, he's also lost two shoe sizes. Recently, he tried on a pair of his old sweatpants and fit both legs into one pant leg. It's even hard for him to believe those old clothes once fit him.

Thomas has been losing an average of 4 pounds a week and has set his sights on reaching 200 pounds by the end of March. But even with a little way to go, his work has paid enormous dividends. His cholesterol is way down, his blood pressure is a solid 110/80 and every trip to the doctor is a good one.

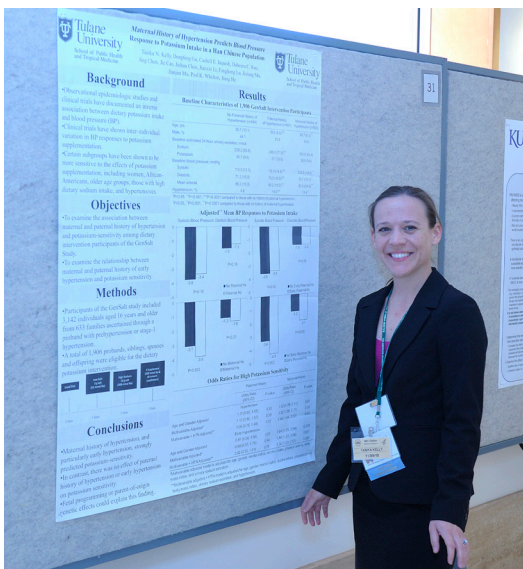
"I feel a thousand times better, there's really no comparison," he said. "I have more energy, I don't sweat, I don't breathe as hard, I can do things I couldn't do before. It's not a picnic, but it's completely worth it. I did it for myself."

As satisfying as it will be for Thomas to reach his goal, he's not completely at ease. He wants to help others struggling with obesity, to tell them they can also make a change. He said he remembers all too well what it felt like to be the biggest guy around.

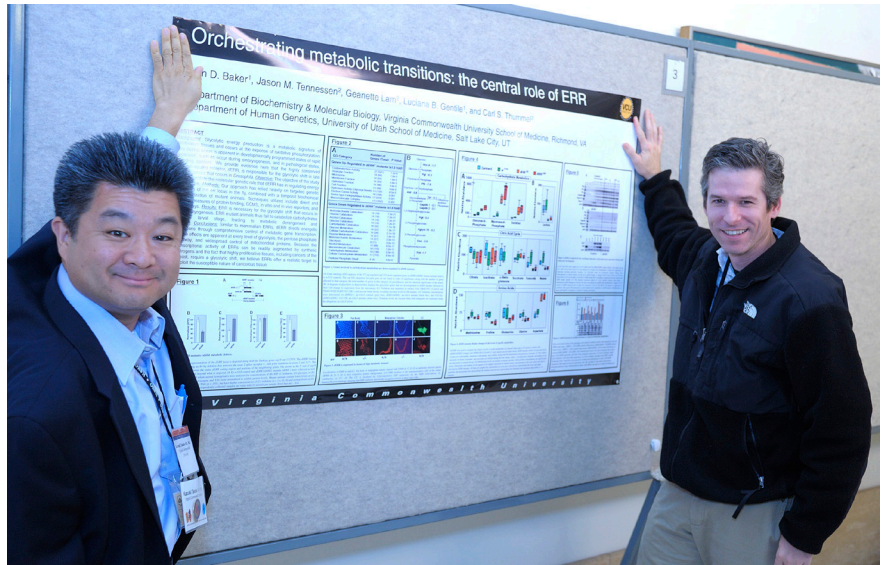
"When you're big, you know that other people are noticing, like when you get on the subway and everything gets quiet, you draw a lot of attention, it's a very uncomfortable feeling," he said. Though people might not say anything, "all eyes are on you, and you know they're thinking, 'Hey this guy is really big.' I can understand how someone else feels who's going through that. I want to tell them you don't have to be that way if you don't want to. I've been on both sides."

He wants to do other things, too. "I'd like to run a marathon," he said. 🏃





Above, Dr. Tanika Kelly, Tulane University BIRCHW scholar, displays her work. At right, Dr. Kazuaki Takabe (l) and Dr. Keith Baker are BIRCHW scholars from Virginia Commonwealth University.



## Women's Health Research Symposium Showcases Interdisciplinary Research

The seventh annual Interdisciplinary Women's Health Research Symposium recently showcased two programs that have helped define women's health research over the past two decades: Building Interdisciplinary Research Careers in Women's Health (BIRCHW, K12) and the Specialized Centers of Research (SCOR) on Sex and Gender Factors Affecting Women's Health.

BIRCHW scholars and SCOR principal investigators unveiled studies considering questions relevant to women's health, including: Are researchers using the appropriate mouse model to study breast cancer progression? How can preterm birth affect a mother's risk of cardiovascular disease later in life? Do female master cyclists have lower bone mineral density than active females who are not cyclists?

The BIRCHW program prepares new and junior faculty for careers in women's health research by providing salary support, mentoring and protected research time. The SCOR program supports women's health and sex differences research by accomplished scientists. It integrates basic, clinical and translational approaches to accelerate the transfer of research findings into clinical practice. Both programs emphasize an interdisciplinary approach.

When the history of the Office of Research on Women's Health is written, "I think the interdisciplinary research will stand out," said Dr. Vivian Pinn, ORWH director, in opening remarks. She said the research focus has widened during the 20 years ORWH has existed. "We know that there are sex differences, even at the molecular and cellular level," she said. "And so we've transitioned from focusing on women's health to focusing on both women's health and sex differences research."

Dr. Alan Guttmacher, director of NICHD, detailed a number of women's health advances and outlined promising areas of future research, including the development of stem cell regenerative therapy to treat conditions such as endometriosis and pelvic floor disorders.

"It's easy to lose track of this, with all the challenges we face, but we really have come a long way," Guttmacher said. Some advances in women's health, he said, can be traced to the work of ORWH. "My belief is that having more women in medicine and biological research over the past couple of decades has made a real difference in terms of progress we've seen in terms of women's health."

A videotape of the day's proceedings can be found at <http://videocast.nih.gov/summary.asp?live=9752>.

## 'Rare Disease Day' at NIH, Feb. 28

NIH will celebrate the fourth annual Rare Disease Day on Monday, Feb. 28 with a day-long celebration co-sponsored by the Office of Rare Diseases Research and the Clinical Center. The event will recognize rare diseases research activities supported by several government agencies and advocacy organizations.

The event will be held in Lipsett Amphitheater, Bldg. 10, from 8:30 a.m. to 5:15 p.m. with a lunch break and poster session from 11:30 a.m. to 1:30 p.m. Attendance is free and open to the public and pre-registration is encouraged.

Organizers have put together an agenda of talks—including two from NIH Bench-to-Bedside Award investigators—and posters and exhibits from many groups relevant to the rare diseases research community. NIH director Dr. Francis Collins will speak at 1:30 p.m.

In association with the Global Genes Project (a grassroots effort to use jeans to raise awareness for rare genetic disorders), organizers urge all attendees to wear their favorite pair of jeans.

The day was established to raise public awareness about rare diseases. There are about 7,000 of them identified in the United States. About 80 percent are genetic in origin and about 75 percent affect children.

For more information and to register, visit <http://rarediseases.info.nih.gov/RareDiseaseDay.aspx>.





## PLAYWRIGHT

CONTINUED FROM PAGE 1

### Top, l:

CC deputy director for clinical care Dr. David Henderson leads Smith on a tour of the Clinical Research Center. She met patients on both a pediatric and an adult care unit of the hospital.

### Top, r:

NIH director Dr. Francis Collins conducts an in-depth interview of Smith in the mode of Bravo's Actors Studio host James Lipton.

### Below:

Smith and Henderson on one of the CRC's interstitial utility floors

PHOTOS: BILL BRANSON

woman play that she's written and is taking on nationwide tour—she did 320 interviews on 3 continents. The total production—perhaps a drama/documentary hybrid with doses of humor—consists basically of Smith armed with a microphone. She uses no costumes or props to speak of, although one character in particular seemed quite comfortable with bottle in hand, occasionally gulping great noisy swallows. Sometimes Smith is seated, but often she's a lone figure standing centerstage in a one-sided conversation. The effect is powerful, intimate.

### 'Organic Poems'

In theaters, Smith becomes a cast of some 20 characters, all of them somehow involved in a crisis of health, either as patient or care provider. For NIH's audience on Feb. 3, Smith gave several excerpts from the full play, introducing us to a crude-speaking rodeo cowboy, a privileged physician working at a public hospital in one of New Orleans's poorest sections, a no-nonsense medical school dean undergoing chemotherapy and a compassionate orphanage founder who comforts children dying of HIV/AIDS.

For about 40 minutes, we saw Smith portray a range of tender emotions, from the cowboy's matter-of-fact perspective on extreme pain, called "Toughness," to the doctor's angry shock at being abandoned during Hurricane Katrina, called "Heavy Sense of Resignation."

"I give everything a title because I really feel like people are speaking their organic poems," Smith explained, in between characters.

Taking on the mannerisms and speech patterns of the late film critic Joel Siegel, Smith revealed the tears of a clown facing his own impending mortality. "Let me down easy," she intoned quietly, using Siegel's words to describe how he had envisioned a gentle hand laying him to rest at the end.

Although it's Siegel's words that Smith adopted

for her play's title, it's the sentiment on courage, as expressed by cowboy Brent Williams, that Smith said keeps pushing its way to the forefront of the work.

"We shouldn't be able to stay on the back of a bull trying to buck you off, cuz we weigh 150 pounds and they weigh over 2,000 pounds," she said, in his husky plain-spoken Western twang. "I think it's determination. I think it comes from inside you what keeps you on that bull." Then, in her own voice, "The theme of toughness runs through this whole play."

### Absorbing the World

An actor, playwright and professor, the multi-talented Smith has also been called the ultimate impressionist. She seemed to see herself at NIH—as on her other sojourns around the world—as more the student.

"The work I've been doing for the last 35 years is to defy the idea that we belong in boxes and categories," she said. "I've been going across the country for a long time now, with a tape recorder, interviewing people with the whole goal of putting myself in people's words the way you would think of putting yourself in people's shoes. I'm trying to absorb America by absorbing the words that people say to me."

NIH director Dr. Francis Collins, who invited Smith to NIH, first heard about Smith some





*Adopting an individual's unique mannerisms, gestures, dialect and speech patterns, Smith brings several characters to NIH's Masur Auditorium stage, including a crude-speaking rodeo cowboy, a compassionate orphanage founder who comforts children dying of HIV/AIDS and the late film critic Joel Siegel, whose words became the title of Smith's play, Let Me Down Easy.*

years ago from his mother, who was also a playwright. Collins said his mother met Smith when they both participated in a discussion group on theater in New York City. Collins's mom—not really a fan of the Big Apple theater scene—came home nevertheless praising this young playwright who had also been on the panel.

His mom told him, “[Smith] understood what theater was all about, that it was about ideas. It was about language. It wasn’t about the big show and the fireworks and the explosions and the fancy dance number. It was about concepts. It was about appealing to people’s spirit and not just their sense of excitement.”

Introducing Smith to NIH, Collins noted, “Every generation produces a few artists who convey powerful messages that touch us with a sense of awe and wonder, but also touch us in terms of our conscience. Anna Deavere Smith is one of those treasures of this generation.”

### Getting ‘People to Sing’

After the performance portion of the program, two chairs and a makeshift coffee table were brought onstage, reminiscent of the simple set for Bravo network’s interview show, *Actors Studio*. Collins, serving as host, put several questions to Smith about her craft, how she chose health care as a topic and what she hopes will result.

“I’m trying to get people to sing,” she said, describing how she approaches folks, gathering the characters she ultimately inhabits. “I’m trying to get them to do interesting verbal things without my having to do anything, because then I know it’s real. I know it’s organic. I want them to reveal themselves to me through language, through the sounds they make.”

Smith acknowledged several misgivings, panicky hours before she embarked on what was essentially a world tour as a scientist, recruiting study subjects for later in-depth emotional examination.

“What am I doing? This is going to be so upsetting. This is going to be so depressing,” she worried aloud, consulting with counselors and advisors just prior to her departure for Rwanda, South Africa and Uganda. That’s not how it turned out, though.

“It was the richest trip,” she recalled. “You know this better than I do. When people are vulnerable is when they’re the most generous. Haven’t you learned this? That some of the people who have the most, the richest people are sometimes the least generous. And people who have the least are so much more willing to give. And people wanted to give me the story of their tragedies and they were so invested in making themselves and everything else better that it was an enormously, enormously hopeful investigation.”

Collins agreed, noting that people who are facing the greatest challenges are often in many ways the people who show the greatest courage. “We see that certainly in the medical environment here at NIH,” he said.

### ‘The Human Side’

As for what message she wants to send, in this era of health care debate, Smith said, “I hope the play successfully reveals the human side of [the dialogue], which can otherwise be tied up and made bloodless by the necessary language of Washington. It’s necessary that it have its formalities, but we must caution ourselves against trusting that this rhetorical arena will save lives.”

She paused briefly, considering her words before adding, “This is a very important debate for us to have. We *should* be talking about what we’re going to do with limited resources. We *should* be talking about the things that disturb us, the ethical questions we have about life, about death, about how it begins, about how it ends and what we as citizens or what the government has to do about it. These are really important conversations for the people to have and I just hope as I take this play across country that it can inspire community leaders to bring people together from both sides of the aisle to hash it out. We can’t just depend on our leaders for this conversation, or the media.”

Closing the program, Collins noted that Smith had toured the Clinical Research Center and met with several NIH staffers and patients. “We’ve been captivated by what you’ve shown us in your mirror,” he said, then asked whether there was any final reflection she wanted to leave with the audience.

Smith responded that NIH had already given *her* a gift: an understanding that NIH has a mission and passion for it.

“I have an enormous amount of wonder whenever I see mission in action in a very materialistic time in history,” she concluded. “When I go places, a lot of people want to know what I hope they take away [from seeing the performance]. I hope you don’t mind, but [this time] I’m the one with the takeaway. I hope you don’t feel robbed. I’m taking away the charge to find mission in my work as an artist and I can’t thank you enough.”



At the Herrick Symposium, NHLBI acting director Dr. Susan Shurin discusses sickle cell as the first molecular disease.



## SICKLE CELL

CONTINUED FROM PAGE 1

*“The doctors told my parents that I probably wouldn’t live to see my 18th birthday. Sickle cell was like a death sentence, but now it’s totally the opposite...”*

ease has led the way for scientific study of human genetics and molecular biology, such that it is among the best understood diseases at cellular and genomic levels,” said NHLBI acting director Dr. Susan Shurin. “Looking ahead, our work must focus on continuing to advance knowledge together. Engagement of patients, communities and providers with investigators and policy makers is crucial to continued progress.”

Herrick, whose landmark paper appeared in the *Archives of Internal Medicine*, noted “the shape of the reds was very irregular, but what especially

attracted attention was the large number of thin, elongated, sickle-shaped and crescent-shaped forms.” Those unusual shapes later gave the condition its name.

Sickle cell disease, also known as sickle cell anemia, is an inherited, life-long condition. People who

have the disease inherit a copy of the gene that causes sickle cell from each parent. The gene codes for production of an abnormal hemoglobin that causes red blood cells to sickle. It affects between 70,000 and 100,000 people in the United States, most of whom are of African or Hispanic descent.

Symposium attendees came together to offer personal and clinical perspectives, address global challenges, review data from ongoing research, discuss therapeutic options and highlight potential treatments.

“We must examine not only the biological origin, but also the non-biological influences, including social, cultural, economic, political and environmental factors,” said Dr. John Ruffin, director of NIMHD. “This is because the transmission, diagnosis and treatment of the disease, and how it is experienced by patients, are powerfully shaped by the characteristics of the societies where it occurs.”

The voices of individuals living with sickle cell

disease resonated throughout the 2 days, alternately inducing tears and cheers. “The doctors told my parents that I probably wouldn’t live to see my 18th birthday. Sickle cell was like a death sentence, but now it’s totally the opposite. I mean, people can live effective, prosperous lives, healthy lives with sickle cell disease, so I think that we’ve come a long way,” said Tiffany McCoy in a featured video. She attended the conference alongside her family. “I have sickle cell but sickle cell doesn’t have me.”

During the second day of the conference, clinical practice guidelines to manage sickle cell disease were previewed. NHLBI is leading the development of the guidelines and a draft chapter on hydroxyurea therapy was made available online, with participants encouraged to provide feedback.

While bone marrow transplants offer a cure to children and teens who have a suitable donor, currently there is no widely available cure for sickle cell disease. Several presentations provided insights into potential therapies involving hematopoietic stem cell transplantation, induced pluripotent stem cells and gene replacement therapy. Such research offers hope to those who have the disease and to those who treat individuals with it.

“I would predict, based on all of the exciting developments here, and many of you in this audience are conducting those, that we are going to get further in the therapeutic developments and ultimately the ability to manage sickle cell disease satisfactorily in the next 10 years than we have in the last century,” said NIH director Dr. Francis Collins. “And I hope if we happen to gather at the 110th anniversary of Herrick’s paper that we will have much to celebrate in terms of the way in which the care of individuals with this disease has taken a major leap forward.” ●



# milestones

## Chacko Named Director of CSR Office

Dr. George Chacko has been named director of the Office of Planning, Analysis and Evaluation at the Center for Scientific Review. He will lead efforts to plan and assess initiatives to enhance the referral and review of NIH grant applications at CSR.



“George brings with him an exceptional set of analytic and leadership skills and a deep appreciation of NIH peer review,” said CSR director Dr. Toni Scarpa. “But we were most impressed by his abilities to think outside the box and turn good ideas into good practices. These skills will be invaluable as CSR continues to work to meet future challenges.”

Scarpa added that Chacko “has nearly 10 years experience as a scientific review officer and review group chief and he is a two-time winner of CSR’s most coveted staff awards.”

Chacko recently won a CSR Architect Award for coordinating CSR efforts in an inter-agency collaboration to review applications for Qualified Therapeutic Discovery Project grants to stimulate the economy. In 2007, he won a CSR Explorer Award for leading CSR efforts to develop and implement the Internet-assisted meeting platform.

Chacko recently served as chief of CSR’s bioengineering sciences and technologies integrated review group. He previously was scientific review officer for CSR’s computational biophysics special emphasis panel. He also coordinated the review of other applications in the biological chemistry and macromolecular biophysics integrated review group.

Chacko came to CSR from the National Cancer Institute, where he was a CRTA fellow, focusing his research on signal transduction in lymphocytes.

Chacko received B.V.Sc. (D.V.M. equivalent) and M.V.Sc. degrees in veterinary medicine and vet-

erinary pathology, respectively, in India. He also received a Ph.D. in biochemistry and immunology at Ohio State University. He began his postdoctoral training at Washington University School of Medicine in St. Louis.

## NIAMS’s Breithaupt Earns Presidential Rank Award

NIAMS Associate Director for Management and Operations W. Gahan Breithaupt is a recipient of the 2010 Meritorious Executive Presidential Rank Award, one of the highest honors in the federal government. The award is given to career civil service executives who have consistently shown integrity, commitment and exceptional service to the public.

HHS Secretary Kathleen Sebelius praised Breithaupt as an “innovative and versatile leader who has consistently demonstrated strength, integrity, diligence and a relentless commitment to the HHS mission.” She also noted that he had “successfully balanced the needs and perspectives of your customers, stakeholders and employees.”

Breithaupt came to NIAMS in 2004 from NINDS, where he was acting executive officer, chief information officer and chief of the Information Resources Management Branch. A senior NIAMS leader and a member of its executive group, he has contributed to numerous trans-NIH activities including the information technology working group, the strategic administrative management planning committee and the performance review board. He has also chaired many SES-level search committees.

“Gahan’s commitment to the ideals of public service is apparent every day,” said NIAMS director Dr. Stephen Katz. “We are proud of the recognition that he, the NIAMS and the NIH have received through this prestigious award.”



## Maas Joins Staff at NIGMS

*Dr. Stefan Maas recently joined NIGMS as a program director in the Division of Genetics and Developmental Biology, where he will manage research grants in the areas of cell growth and differentiation as well as regulatory signal transduction networks. Prior to joining NIGMS, he served as an associate professor of molecular biology at Lehigh University. Maas earned a B.S. in biochemistry from the Free University of Berlin and a Ph.D. in molecular and cellular neurobiology from the University of Heidelberg.*

## Grantees Publish Orangutan Genome Sequence

It is easy to feel a kinship with orangutans when looking into their soulful eyes and observing their socially complex behavior. Perhaps that's

because orangutans and humans share 97 percent of their DNA sequence, according to an analysis of the great ape's genome reported by an international group of scientists.

Orangutans, known for their distinctive auburn hair, are primarily tree dwellers native to the southeast Asian islands of Sumatra and Borneo. The DNA sequence published in the Jan. 27 issue of *Nature* is from a female Sumatran (*Pongo abelii*) orangutan. In addition, five Sumatran and five Bornean (*Pongo pygmaeus*) orangutan genomes

were sequenced at a less detailed level. The orangutan is the third non-human primate to have its genome sequenced, after the chimp and rhesus macaque. Of the great apes, orangutans are the most distantly related to humans, while chimpanzees are the most closely related.

Researchers can now leverage the orangutan genome sequence to learn more about the biology of this endangered species and to identify what has been added or deleted in the evolution of primate and human genomes that may have contributed to unique human characteristics.

### Scientists Identify Genetic Cause of New Vascular Disease

Researchers at the Undiagnosed Diseases Program have identified the genetic cause of a rare and debilitating vascular disorder not previously explained in the medical literature. The adult-onset condition is associated with progressive and painful arterial calcification affecting the lower extremities, yet spares patients' coronary arteries. The new disease finding was published Feb. 2 in the *New England Journal of Medicine*.

The rare arterial condition caused by calcium buildup in arteries below the waist and in the joints of a patient's hands and feet has been observed in nine individuals from three unrelated families, who are the only people known to have the disorder. The researchers refer to the condition as ACDC, or arterial calcification due to CD73 deficiency. Although symptoms of the

disorder include leg and joint discomfort, medical evaluations of the patients ruled out rheumatoid arthritis or other joint-related problems. Genetic analyses performed by the researchers suggested a novel disorder and pinpointed the cause of the condition as mutations, or variants, in the NT5E gene.

"This is the first novel disease discovery identified through the collaborative and interdisciplinary approach employed by clinical researchers in the NIH Undiagnosed Diseases Program," said NIH director Dr. Francis Collins. "This disorder previously baffled the medical field and evaded diagnosis when conventional methods were used."

"Vascular calcification often results from poor diet and lack of exercise," said study coauthor Dr. William Gahl, director of the UDP. "The calcium buildup in arteries of our patients, however, arises because the systems to inhibit it are not working in their cells. We hope that an understanding of this faulty mechanism will guide us in providing helpful treatments for these patients."

### Level of Tumor Protein Indicates Chances Cancer Will Spread

Researchers at NIH and the University of Hong Kong have discovered that high levels of a particular protein in cancer cells are a reliable indicator that a cancer will spread.

By measuring the protein's genetic material in tumors that had been surgically removed from patients, along with measuring the genetic material from surrounding tissue, the researchers could predict at least 90 percent of the time whether a cancer would spread within 2 years.

The findings, which appeared in the *Journal of Clinical Investigation*, raise the long term possibilities of new tests to gauge the likelihood that a cancer will spread and, ultimately, of a treatment that could prevent cancer from spreading.

The protein, known as CPE-delta N, is a form of carboxypeptidase E (CPE). Ordinarily, CPE is involved in processing insulin and other hormones. CPE-delta N was present in high amounts in tumors that had spread and, to a much lesser degree, in surrounding tissues.

"Testing for CPE-delta N, if combined with existing diagnostic methods, offers the possibility of more accurately estimating the chances that a cancer will spread," said NICHD director Dr. Alan Guttmacher, whose institute supported the study. "Conceivably, a patient's CPE-delta N levels could be a key guide in individualizing their cancer care to improve outcome."



*NHGRI-supported researchers have sequenced the genome of the orangutan, which belongs to the primate family.*

PHOTO: YERKES NATIONAL PRIMATE RESEARCH CENTER





### Acclaimed Pianist Plays Second CRC Concert

*World-renowned Hungarian pianist Adam György shared his musical talent for the second time at NIH when he gave a free concert Jan. 25 in the atrium of the Clinical Research Center. The CC and the National Institute on Alcohol Abuse and Alcoholism sponsored the performance, which included works by Mozart, Chopin and Liszt. The concert was part of the Clinical Center Piano Concert Series, providing music for patients, family members, visitors and staff as part of the healing environment of the CC. György first appeared in the atrium on Oct. 20, 2009, and a feature story about him appeared in the Nov. 13, 2009 edition of the NIH Record (see [http://nihrecord.od.nih.gov/newsletters/2009/11\\_13\\_2009/story4.htm](http://nihrecord.od.nih.gov/newsletters/2009/11_13_2009/story4.htm).)*

PHOTOS: ERNIE BRANSON



Have a question about some aspect of working at NIH? You can post anonymous queries at [www.nih.gov/nihrecord/index.htm](http://www.nih.gov/nihrecord/index.htm) (click on the Feedback icon) and we'll try to provide answers.

**Feedback:** Is there any department on campus that might be available for safety training (i.e., AED, CPR)? Something that might cover emergencies when waiting for an ambulance or police?

**Response from the Office of Research Services:** The Division of Occupational Health and Safety provides several courses in this area. The first class is a Health Care Provider Cardiopulmonary Resuscitation class designed for health care providers but open to anyone. Other courses are designed only for the lay person. The first is a Heart-saver AED course and covers both CPR training and the use of automated external defibrillators. A Heartsaver First Aid course is also available. All classes offer instruction in adult, child, infant CPR, use of a pocket mask and use of AED. Classes are held in Bldg. 31 and registration can be done online at [www.ors.od.nih.gov/ors\\_cpr\\_training/scripts/cpr\\_calendar.asp](http://www.ors.od.nih.gov/ors_cpr_training/scripts/cpr_calendar.asp). A course on adult CPR, use of pocket masks and use of the AED can also be arranged at your site. To schedule one, contact Mike Dunn at (301) 496-2960. More information is available at [http://dohs.ors.od.nih.gov/cpr\\_training.htm](http://dohs.ors.od.nih.gov/cpr_training.htm).

**Feedback:** Every day there is one or more ASG security vehicles parked outside Bldg. 31 on the Cedar Lane side. Why are they there? What are they doing? Is there a problem with security in Bldg. 31?

**Response from ORS:** The contractor, ASG, is working in Bldg. 31 on the new Emergency Command Center as well as upgrading and repairing video security equipment for ORS and installing card readers for various institutes and centers. The contractor possesses an authorized and current contractor parking permit issued by the parking office. There is not a security problem in Bldg. 31.

## ORWH, Partners Share Research on 'Polytrauma'

Of the 2 million soldiers and Marines deployed to Iraq and Afghanistan, 9-18 percent return with symptomatic mild traumatic brain injury (TBI) from repetitive exposure to improvised explosive devices. "There is growing concern that multiple concussive events from any cause may set in motion pathogenic processes that may later emerge as neurodegenerative dementing disorders such as Alzheimer's disease," an NIH researcher reported during a recent conference at Natcher Bldg.

Dr. Elaine Peskind of the VA Puget Sound Health Care System and the University of Washington is a current NIA and VA grantee studying Alzheimer's disease, post-traumatic stress disorder and blast concussion TBI. She presented the opening address at the 3rd annual Trauma Spectrum Conference sponsored by NIH, DoD and VA. The conference is a forum for leading experts to share the latest approaches in research and treatment focused on polytrauma.

Peskind described an unprecedented health problem facing veterans: the ratio of wounded to killed in battle has changed substantially and more troops are coming home who have survived blast exposure and multiple concussive events.


Peskind said it is not known whether sports concussion is similar to blast concussion. Repetitive sports concussion has been associated with a rare mid-life dementing disorder known as chronic traumatic encephalopathy. However, any head injury with loss of consciousness is a risk factor for AD, which occurs in one-third to one-half of people over age 85.

Peskind presented data from 35 veterans with blast-associated mild TBI and 13 Iraq war veterans without blast exposure. Results of studies using four brain-imaging techniques suggest structural and functional changes due to blast that are not explained by co-morbid PTSD. She cautioned that more data and analysis are needed.

A presentation by Dr. Jan Jasiewicz described "smart technology," an interactive system that uses sensors and other technology to provide memory cues, boost mobility and promote a range of other clinical goals. He said the system is expected to shorten recovery times and assured that the VA is working on a variety of research and technology to benefit veterans.



*NIA grantee Dr. Elaine Peskind of the VA Puget Sound Health Care System and the University of Washington presents the opening address at the 3rd annual Trauma Spectrum Conference.*

The Office of Research on Women's Health co-coordinated the 2-day conference. ORWH director Dr. Vivian Pinn highlighted NIH-funded clinical trials research related to service members and their families and described a new NIH web portal that provides information and resources specific to women serving in the military; visit <http://sis.nlm.nih.gov/outreach/whrhealthtopics.html#b014>. 

## Patterson Named Associate Director for Science Policy

Dr. Amy Patterson has been named NIH associate director for science policy (ADSP), effective Jan. 16. She had been serving as acting ADSP since fall 2008. She was director of the Office of Biotechnology Activities within the NIH Office of Science Policy when named to serve as acting ADSP. Previously, she had been a postdoctoral fellow at NIH after completing a residency in internal medicine at Memorial Sloan-Kettering Cancer Center and New York Hospital, where she was assistant chief resident. She then moved to the FDA, serving as deputy director of the division of cellular and gene therapies and senior medical officer in the Center of Biologics Evaluation and Research before returning to NIH. "I am delighted that we will all continue to benefit from her leadership of the Office of Science Policy," said NIH director Dr. Francis Collins, who made the appointment.